Experiences of sleep hygiene education as an intervention for sleep problems in children with developmental disabilities: Findings from an exploratory study

Sutton, Julie; Huws, Jacqueline; Burton, Christopher

British Journal of Learning Disabilities

DOI:
10.1111/bld.12270

Published: 01/09/2019

Peer reviewed version

Short title: Sleep hygiene education and children with developmental disabilities- exploratory study.

Experiences of sleep hygiene education as an intervention for sleep problems in children with developmental disabilities; findings from an exploratory study.

(5000 words including references)

BILD manuscript.

ACCESSIBLE SUMMARY:

- Sleep hygiene education (SHE) is a “behavioural” intervention which helps parents create the best sleeping conditions for their child. It is often used to improve sleep problems that children with developmental disabilities have.
- SHE includes advice around creating bedtime routines, calming bedrooms and eating healthily. Lots of health and social care professionals use SHE, but there are not many research papers which show the best way to support parents to try out the advice.
- This research tells the story of nine parents and eleven professionals who have used SHE to help improve children’s sleep problems.
- Their experiences are important in research literature and will help other services improve the way SHE is used in the future.

ABSTRACT:

Background:

Sleep hygiene education (SHE) is a familiar intervention for addressing behavioural sleep problems in children with developmental disabilities that involves advising parents on sleep promoting behaviours however, it is supported by a limited evidence base.

Materials and Methods:

This exploratory study aimed to enhance qualitative understanding and explore stakeholder perceptions about experience, current practice and ideas around the implementation of SHE. Parents of children with developmental disabilities and sleep problems (n=9) and sleep practitioners (n=11) took part in semi-structured interviews and focus groups, and data were thematically analysed.

Results and discussion:

The analysis identified four parent themes: Beliefs about sleep problems; Getting professional help; Ways of knowing about sleep; and, Visions of sleep support. Two practitioner themes were also identified: Sleep service accessibility; and, Inconsistent sleep support.

Conclusion:

The findings provide rich insights into how parents of children with developmental disabilities experience sleep problems, and how SHE is currently implemented. These have implications for both policy and practice.

Keywords:

Sleep hygiene education, experiences, children, developmental disabilities, sleep, thematic analysis.

Introduction/Background:

Severe and enduring sleep problems are common in children with developmental disabilities (Table 1), and the detrimental effects to well-being are well documented such as compromised growth and impaired cognitive performance (Bonuck & Grant, 2012; Tietze et al., 2012). Difficulties with sleep are also associated with negative outcomes for the family such as heightened stress and relationship breakdown (Bourke-Taylor et al.,2013; Richdale et al., 2000). To ensure appropriate treatment, current evidence advises sleep practitioners (professionals who support families with sleep problems) to identify and treat physical causes for example pain, epilepsy or breathing difficulties, and assess whether sleep problems have a behavioural origin or are linked to the way parents manage them (Malow et al., 2013; McDaid & Sloper, 2009). Sleep hygiene education (SHE) is a typical first intervention for behavioural sleep problems, and aims to educate parents about behaviours that promote healthy sleep in children (such as consistent bedtime routines, appropriate sleep timing, relaxation techniques and healthy eating) (National Institute for Health and Care Excellence, 2013; Vriend, Corkham, Moon & Smith, 2011).

SHE is commonly implemented in combination with other behavioural strategies such as graduated extinction or sleep restriction (Jan et al., 2008), implying that it is a necessary primary step but insufficient as a stand-alone intervention. Notwithstanding, if SHE is implemented inadequately, subsequent interventions often fail or are less effective (because the basic conditions for sleep - such as a darkened room or comfortable bed - have been overlooked) (Vriend et al., 2011). This highlights how there is a limited conviction that SHE is a credible and effective intervention for behavioural sleep problems in children with developmental disabilities.

A scoping review of SHE and children with developmental disabilities (Author 1 [ ]) revealed limited evaluative evidence and qualitative research exploring parents' and sleep practitioners' experiences. Most sleep intervention studies focused on multi-component SHE

(SHE combined with other behavioural interventions). Only two studies investigated the effectiveness of SHE as a stand -alone intervention, and were limited to children with Autistic Spectrum Disorder (Adkins, Molly et al., 2012), or were of poor methodological quality (Piazza et al.,1997). One qualitative study explored ~~stakeholder~~ sleep practitioner and parent views of multi-component SHE (Beresford et al., 2012) and reported facilitators to intervention success such as continued practitioner support, building trusting parent/practitioner relationships and barriers including parents' resilience, marital conflict and child's condition. However, as this study focused on multi-component SHE, ~~study~~ findings had limited applicability to SHE as a stand-alone intervention. Furthermore, the scoping review found no evidence relating to organisational or policy factors, and how this affected intervention success. These findings highlight the need for further inquiry into how SHE works to improve sleep in children with developmental disabilities. The present exploratory study aims to build upon the evidence base in three broad ways:

1. Exploring parent and sleep practitioner (stakeholder) perceptions of SHE.
2. Reporting current SHE practice and how this relates to scoping review findings.
3. Exploring how SHE should be structured and implemented.

- ~~Reporting current SHE practice and how this relates to scoping review findings.~~
- ~~Exploring stakeholder perceptions of SHE.~~
- ~~Exploring how SHE should be structured and implemented.~~

[Table 1 to be inserted here] Operational definition of developmental disabilities. ~~(~~This has been specifically developed for the purposes of this study and encompasses a variety of neurological conditions~~).~~

METHODS:

Research design:

A participatory methodology was adopted which focuses on research which is collaborative in design, views participants as equal research partners, and incorporates an agenda for

change (Creswell, 2007; Reason & Bradbury, 2001). This exploratory study was carried out as a preliminary step of a broader experience based co-design study ~~(~~using the King's Fund (2014) toolkit~~)~~ involving parents and sleep practitioners as co-researchers (Author publication accepted Nov 2018 to be inserted here), ~~and its~~. Exploratory study findings informed the development of joint stakeholder service improvement groups to advance understanding of SHE intervention complexity to improve ~~SHE~~ delivery.

Ethics:

Institutional [IDENTIFIERs TO BE INSERTED FOLLOWING REVIEW], Research Ethics Committee (REC) and local Health Board Research and Development internal review approval was obtained. All participants received participant information, contact and consent forms, and before the interviews commenced, they were asked to discuss any concerns before consenting to participate in the research.

Procedure:

A convenience sample of nine parents and sixteen practitioners were recruited from health and social care teams and UK voluntary organisations supporting families of children with developmental disabilities (Table 2).A chain sampling strategy (Patton, 2015) was adopted by author 1, which involved asking well-situated people from local health board and partner voluntary organisations to identify prospective participants. Parents were assigned pseudonyms and sleep teams given a team code to maintain anonymity. Codes prefixed with the letter 'H' referred to local health board teams, 'S' to social care teams, and 'V' to voluntary organisation teams. Teams were further categorised into 'consultation teams' who had a direct role in assessing sleep problems and designing SHE interventions, and 'signposting teams' which gave ad-hoc SHE advice and directed families to appropriate services. Consultation teams either specialised solely in sleep (ST1 and VS1) or offered sleep advice as part of a broader range of health services (HT1 and HT2). Sleep practitioner

participants were also given codes beginning with the code assigned to their team followed by the initials of their professional role.

[Table 2 to be inserted here] Parent & Practitioner sample.

Parents met the inclusion criteria if (i) they had a child with developmental disabilities aged 3-18 years with experiences of sleep problems, and (ii) had some experience of SHE to address their child's sleep difficulties. Parents younger than 18 years old or those who did not have any experience of SHE were excluded. Parents of typically developing children with sleep problems were also not eligible to take part in this study. Practitioners met the inclusion criteria if (i) they had at least six months experience of supporting families of children with developmental disabilities aged 3-18 years with sleep problems, and (ii) were experienced in the application of SHE. Sleep practitioners who only supported families of typically developing children, or adults with learning disabilities were excluded. Sleep practitioners with less than six months sleep work experience and/or no experience of SHE were also excluded. From the sample, six parents took part in a first round of 90-minute semi-structured one-to-one interviews, and nine practitioners participated in a two-hour focus group. The research team developed discussion area guides based on the scoping review findings, Author 1's background clinical Learning Disability Nursing experience, and the three broad study aims.

Analysis:

Interviews and focus groups were digitally recorded to facilitate verbatim transcription, and potential identifiers were anonymised after transcription. Transcripts were checked by author 2 to ensure accuracy. Parent and sleep practitioner data was analysed as two separate data sets. Analysis involved the inductive development of themes which were data driven, and followed the thematic analysis process recommended by Braun and Clarke (2006). Preliminary parent and practitioner themes were then validated in an additional round of interviews with five parents, and in a second focus group attended by five practitioners taken

from the purposive sample. This process of respondent validation shows how participants were actively involved in checking the authenticity of data and testing and developing constructions, ~~and~~ which demonstrates a commitment to participative inquiry (Guba & Lincoln, 1989). Data from the second round of interviews and focus group were transcribed, checked and a second level thematic analysis was performed; this produced a set of refined themes.

FINDINGS:

The analysis illuminated four parent themes, and two practitioner themes:

Parent themes:

1. Beliefs about sleep problems.

2. Ways of knowing about sleep.

3. Getting professional help.

4. Visions of sleep support.

Practitioner themes:

1.Sleep service accessibility.

2. Inconsistent sleep support.

1. Beliefs about sleep problems.

The majority of parents (N-7) explicated the constant struggle they faced coping with children's sleep problems, and that this struggle was usually experienced on a nightly basis and over a period of many years. A sense of relentlessness pervaded parents' lives, and a negative impact on parents' mental health and well-being was evident:

"It's almost like a form of torture, (short laugh). Because you will just get off to sleep and then you think, especially when she was younger, think oh she's up again. You know and it's exhausting"

(Maureen)

This sense of relentlessness could lead to resignation towards a child's sleep problems, and parents commonly talked about becoming accustomed to, or 'normalising', sleep difficulties. One parent described her waning hope that any sleep improvement could be achieved:

"*If he's not wetting the bed four times and he's not sleep walking, and I don't have to deal with a major meltdown at two am…that's a result (laughs)…I'm not looking for perfection..(..) just liveable"*

(Stella)

Parents identified the negative impacts of sleep problems on children's education, mood and behaviour. One parent linked her son's sleep deprivation with waking up feeling un-rested and grumpy, which in turn affected his behaviour and ability to concentrate in school:

"When he wasn't having a good chunk of sleep his behaviour would obviously be ..erm, be very poor and in school as well, his learning was being affected."

(Corrine)

2. Ways of knowing about sleep.

Four parents directly attributed their child's sleep problems to their disability diagnosis, and described how this positively affected their attitude towards managing sleep problems. However, this could then negatively impact upon seeking other possible sleep problem

causes. This highlights a pre-implementation barrier towards starting the process of seeking professional sleep help.

> "*So I thought 'Oh, well that explains it then…' I kind of took it as part and parcel."*
>
> (Kim)

The majority of parents (n-7) reported utilising 'common-sense' parenting strategies, such as the necessity of instilling bedtime routines; however, these were inadequate in fully solving their child's sleep problems. In the absence of professional sleep support, ~~some~~ six parents experimented with additional strategies, such as co-sleeping or allowing their child to use electronic media (approaches that are incompatible with usual SHE advice). In evidence was parents' despair in not knowing what else to do, and mixed levels of awareness relating to what was recommended practice or not. Two parents resorted to independently 'experimenting' with the use of weighted blankets to help settle their children to sleep. This is a practice that is not supported by evidence, and both parents seemed to be unaware of the potential safety risks involved (both parents were advised to seek Occupational Therapist guidance to ensure correct use, once the interview and recording had stopped):

> *And I've ordered him a ... a weighted blanket (..):. so I'm just hoping that that will help, so he wasn't expecting the cuddles off me (..)So I've just ... done that off my own ... you know, off my own steam basically (..) researched it and done it."*
>
> (Georgia)

3. Getting professional help.

~~Some~~ Three parents viewed their child's sleep problem as a private parenting issue; others (n-4) expected generic practitioners ~~(~~such as teachers or General Practitioners~~)~~ to take some professional responsibility for addressing such issues. Parents acknowledged that there was a need for tenacity in sourcing disability specific help, but were often left feeling despondent when generic practitioners were not aware of what services were available:

> *"That really struck me, nobody knew where to point us, you know, the school, not even a doctor knew."*
>
> (Sally)

Moreover, ~~some~~ four parents described how they had struggled to convince both generic and sleep practitioners to take the concerns that they had about their child's sleep seriously, ~~Some~~ Three parents had been successful in receiving sleep help from specialist sleep consultation teams; although one expressed surprise and serendipity that they were able to access such support in a timely manner though, as they had initial low expectations of ever receiving help:

> *"I didn't think I'd get any help, I didn't think anyone would actually ... take me seriously, just think oh, you know ... just get on with it. But Dr '..' actually put me through to the (..) team."*
>
> (Gloria)

4. Visions of sleep support.

Five parents reflected on how the sleep medication, Melatonin, had been offered to treat their child's sleep problems, and all described disappointment that this was offered without having their child's sleep problems formally assessed. Parents indicated that this over-simplified children's sleep difficulties, and felt that decisions to introduce medication was rushed and inadequately informed:

> "*It was just purely discussion, and then they just wrote the prescription."*
>
> (Corrine)

All parents were offered broad-based SHE advice from generic practitioners, and reported mixed levels of satisfaction with such standardised sleep help. However, all parents expressed a feeling of needing something else such as bespoke evidence-based strategies tailored to their individual child's needs:

> "*There was no extra support there, nobody sort of said 'Oh we can come out and monitor how he goes to sleep at night, or go through with you how you put a sleep routine together (..) maybe that could have helped."*
>
> (Corrine)

The geographical location of where sleep support ~~(~~such as assessment and planning~~)~~ should be delivered was important to six parents. Having to attend clinical appointments away from the naturalistic environment of the child and family's home was deemed inappropriate, and was often associated with logistical challenges around transportation and time pressures. Parents expressed a preference for sleep support to be centred within their home as it could help sleep practitioners to understand the nuances of each child's sleep problem and unique family situation:

> *"I think somebody coming to the house, like Super Nanny, to see what's going on would be brilliant. Because there might be things you don't notice that you're doing (..) that could be better."*
>
> (Sally)

The need to feel emotionally safe when discussing sleep problems was also associated with the location of sleep support. For example, one parent described feelings of anxiety and power imbalance when attending a sleep clinic:

> "*Those are the worst type of appointments because…you know your heart's in your stomach by the time you've walked through the door, (..) the third time I went I took my mum with me(..)It's just I needed someone in my corner.(..) I think some places are too, just clinical. And they don't put you at your ease."*
>
> (Gloria)

[1] 'Super Nanny' is a reality television programme where parents receive parenting advice from an

Practitioner themes:

1. Sleep service accessibility.

Three sleep practitioners described how parents' beliefs about sleep problems impacted on their drive to find sleep help. Practitioners described how parents sometimes believed sleep problems were an inevitable part of a child's disability, and that this reinforced a need to carry on coping, regardless of the impact of the sleep problem on the child and family:

> "*People might assume the sleep problems are due to any disability the child has and don't realise (..) and just think 'Oh we need to get on with this'."*
>
> (VFO- Voluntary organisation family officer)

Five practitioners were concerned that generic practitioners were inadequately informed about the role of sleep consultation teams, and this culminated in poor signposting. As such, specialist teams were often poorly promoted, and this

introduced an element of chance in parents' quests of finding sleep support which was ~~(~~demonstrative of another pre-implementation barrier~~)~~:

> *"It's about who you happen to ask about who you happen to phone or email."*
>
> (VSP- Voluntary organisation sleep practitioner)

Three practitioners also described the pre-implementation challenges that parents faced in negotiating sleep consultation referral systems, and there were often a myriad of different stipulations relating to the child's diagnosis, age and postcode. Different routes of referral were also apparent, whereby some services allowed open access for parents, whilst others involved 'gatekeeping' professionals first. It was clear that these factors posed access barriers, delayed timely sleep support, and masked the true magnitude of the need for sleep services:

> "*We're only working with children who have been referred and they are open to somebody else so it's the internal referrals and I'm sure there are lots of other children out there who are not open to our service."*
>
> (SCP- Social care team clinical psychologist)

2. Inconsistent sleep support.

Discussions amongst seven practitioners revealed inconsistencies in the type and comprehensiveness of sleep assessment processes used across different sleep consultation teams. Seven practitioners reported using sleep diaries, but offered varying levels of parental support to complete this task, with some using 'home-grown' tools (n-3), whilst others (n-4) used commercially available sleep history questionnaires or validated sleep outcome measures. There was also considerable variation in the extent to which practitioners interpreted assessment findings to ascertain sleep problem causes, trigger referrals to support services, and design customised SHE advice. Some participants (n-2)

did not discuss issues relating to assessment interpretation; whereas others (n-5) described a deep understanding of the need to base advice on assessment findings:

> *"If it's a behavioural disorder we can pick it up during the sleep questionnaire the diaries you know not far down the line, but if it's anything medical, we'll refer straight back and very often we can help things like sleep studies happening."*
>
> (VSP- Voluntary organisation sleep practitioner)

Six practitioners reported how sleep consultation team VS1 and the signposting teams gave families standardised SHE advice, unsupported by practitioners ~~(~~and prior to sleep assessment~~)~~, with the intention of empowering parents to make a positive start on the fundamentals of SHE. However, four practitioners ~~it was~~ concluded that offering customised SHE advice underpinned with rationale, and following interpretation of sleep assessment data, was preferable. Practitioners felt that ad-hoc advice carried the risk of families interpreting the advice incorrectly, viewing it as too simplistic; it could also lead to families feeling that practitioners were overlooking their child's sleep problem:

> "*I think it can be quite damaging to just deliver sleep hygiene advice as a first port of call (..) parents, sometimes think by painting my child's bedroom neutral colours and taking out all the toys, that this is going to solve the problem, it can be taken as "you're not taking me serious."*
>
> (VSP- Voluntary organisation sleep practitioner)

Disparity also existed around the intensity and duration of support offered to parents to follow SHE advice. This varied from sporadic visits offered by VS1 to intensive visits within a short time frame offered by HT1. This disproportionate provision of support from different teams meant that parents received markedly different levels of assistance to apply SHE

advice. Three practitioners also suggested that parents could be supported to implement SHE advice if they had the support of paid parent buddies or experts:

> "*It's very powerful to have a parent as a buddy and as I agree with you really, it's more kind of moral support, cause I was there and I've been through it and you will get through it."*
>
> (SCP- Social care team clinical psychologist)

Discussion

The analysis demonstrates parents' need to share experiences of their daily realities of living with their child's sleep problems, and the impact that this has on the family. Within their narratives, parents emphasised a sense of relentlessness and resignation when managing sleep problems, and the need to normalise their situation. The implication is that practitioners should seek to develop a deep empathy with a parent's situation before the implementation of SHE advice is considered. This substantiates the limited qualitative evidence reported in the SHE scoping review (Beresford et al., 2012) around building supportive parent/practitioner working relationships. Other study findings were largely un-explored in this scoping review, and reveal new strands of evidence to inform understanding of the complexities of SHE.

Findings reveal parents' views on intuitive, broad based SHE advice (commonly implemented prior to professional involvement) and how they find it necessary, but insufficient in solving their child's sleep problems. In the absence of, or whilst waiting for, professional help, parents also described the compulsion to experiment with strategies which may contradict usual SHE advice, such as the

use of electronic media (Sasseville, Paquet, Sevigny & Hebert, 2006). Although helpful for short-term coping, such strategies can mask, reinforce or sometimes worsen sleep problems; this is an area of concern which highlights the need for practitioners to be mindful of existing coping strategies, and alerts policy makers for the need for early intervention.

When parents' believed disability to be the sole cause of sleep problems, this could deter them from seeking help. This chimes with the 'diagnostic overshadowing' bias whereby an individual's underlying health needs are passed over and attributed to a disability (Mason, 2007; Mason & Scior, 2004). Similarly, there was agreement between stakeholder groups about generic practitioners' poor awareness of the existence and role of sleep consultation teams, and the pre-implementation barrier this posed. Only parents provided evidence of their struggles to persuade generic practitioners to take sleep concerns seriously, indicating a lack of practitioner awareness that this hurdle existed. Such pre-implementation challenges concur with other research findings (Family Fund, 2013; McDougall, Kerr and Espie, 2005), and illuminate the testing beginnings of parents' sleep improvement trajectory. These findings can be used to enhance understanding about how initial contacts with services can be improved.

The findings from the interviews with practitioners highlighted the additional pre-implementation barrier that parents have when navigating the complex referral criteria of different sleep consultation teams. Overall, the diverse range of referral criteria implied a level of inequitable service provision and highlighted a need for greater inclusivity. The setting of restrictive access criteria may be an attempt at rationing scarce resources; however, it is suggested that this demonstrates how individuals with disabilities are a marginalised group that often receive unequal and inadequate healthcare (Atkinson et al., 2013; Department of Health, 2015; Emerson, Baines, Allerton & Welch, 2012).

Inequity in SHE provision was also evident across consultation teams' assessments, and parental support processes, and practitioners revealed that parents would receive a markedly different approach depending on which team they engaged with. This indicates that there is a need for a more consistent approach to SHE delivery across teams to ensure parents received an equitable service. As a new initiative, practitioners suggested incorporating paid parent buddies into consultation teams as an extra support mechanism, which mirrors broader literature highlighting the positive contribution of lay health workers (Glenton et al., 2013; Kennedy, Milton and Bundred, 2008).

Parents and practitioners agreed that SHE advice should be based on sleep assessment findings and tailored to individual need. In practice however, advice was often standardised. Whilst it could be argued that standardisation represents the most cost-effective and least labour-intensive approach in healthcare delivery (Minvielle, Waelli, Sicotte and Kimberly (2004), findings indicated that parents preferred customised advice over that which was broad-based, and possibly inappropriate.

Parents also described how Melatonin was frequently prescribed to treat their child's sleep problem without a prior sleep assessment, and how they were disappointed that this was the primary intervention offered. Broader literature demonstrates how medication should not be the first-line intervention, and that it should supersede behavioural therapy such as SHE (Appleton et al 2012; National Institute for Health and Care Excellence, 2013). Findings suggest it is important to recognise that SHE is commonly implemented as part of a broader package of care which includes medication.

Lastly, in exploring how SHE should be delivered, parents talked about the importance of place. Most parents expressed a preference for home visits based on familiarity, logistics

and feeling emotionally safe when required to discuss the sensitive topic of their child's sleep problems. There is evidence that indicates that bespoke, supportive and flexible one-to-one home visits are favourable for some families (Beresford et al., 2012; Weiskop et al., 2005). Findings therefore suggest that service providers need to acknowledge the benefits to families of assessing sleep problems and implementing SHE at home and how place can potentially affect intervention outcomes.

Strengths and Limitations:

Study strengths include the broad range of differing SHE experiences captured within the parent sample and the varied representation of sleep consultation, signposting, social care, health and voluntary organisation teams. The limitation is noted that ~~It is noted that~~ the present findings represent the experiences of mothers of children with DD, and the views of fathers were not explored therefore ~~Moreover, the sample of parents had a broad range of differing SHE experiences;~~ further research would be of benefit which focussed on the SHE experiences of a broader and more representative group of care givers.

.

Conclusion:

This study has added to the evidence base underpinning SHE, by providing a qualitative analysis of how parents of children with DD experience behavioural sleep problems, and how SHE is currently implemented. The findings have illuminated the complexities of SHE, and demonstrate the multiple factors which can affect intervention success. In conclusion, service leaders and organisations should recognise the need to further invest in sleep consultation teams to ensure SHE is delivered in a timely and equitable manner, comprehensively supported by competent practitioners and parent experts. Furthermore, awareness should be raised of the significant pre-implementation barriers facing parents in their quest to secure sleep help.

Recommendations for practice:

- **Ensure equitable, early and timely sleep intervention to limit parental experimentation with coping strategies incompatible with usual SHE advice.**
- **Consider the involvement of paid parent buddies in sleep consultation services.**
- **Ensure SHE advice offered is customised according to sleep assessment findings rather than broad-based.**
- **Acknowledge the benefits of assessing and treating sleep problems in the home environment.**

Recommendations for future research:

- **Utilise exploratory study findings to inform a co-design study to advance understanding of SHE intervention complexity to improve delivery.**

References

- Adkins, K.W., Molloy, C., Weiss, S,K., Reynolds, A., Goldman, S,E., Burnette, C., Clemons, T., Fawkes, D., & Malow, B,A. (2012). Effects of a standardised pamphlet on insomnia in children with autism spectrum disorders. *Pediatrics, 130*, Supplement 139-44. doi: 10.1542/peds.2012-0900K.
- Appleton, R. E., Jones, A, P., Gamble, C., Williamson, P.R., Wiggs, L., Montgomery., …..P Gringras, P. (2012). The use of Melatonin in children with developmental disabilities and impaired sleep: A randomised, double-blind, placebo-controlled, parallel study (MENDS). *Health Technology Assessment, 16*(40), 239. doi: 10.3310/hta16400.
- Atkinson, D., Boulter, P., Hebron, C., Moulster, G., Giraud-Saunders, A., & Turner, S. (2013).*The health equalities framework.* Improving health and lives. Learning

disability observatory. Retrieved from http://www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf.

- Author 1(…) DETAILS TO BE PROVIDED.
- Beresford, B., Stuttard, L., Clarke, S., Maddison, J., & Beecham, J. (2012). *Managing behaviour and sleep problems in disabled children: An investigation into the effectiveness and costs of parent-training interventions. DFE-RR204. Department for Education Research Report*.(pp. 37-54). London: Department for Education.
- Bonuck, K., & Grant, R. (2012). Sleep problems and early developmental delay: Implications for early intervention programs. *Intellectual and Developmental disabilities,* 50(1), 41-52. doi:10.1352/1934-9556-50.1.41.
- Bourke-Taylor, H., Pallant, J,F., Law, M., & Howie, L. (2013). Relationships between sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities. *Journal of Paediatrics and Child Health*. 49, 775–782.doi:10.1111/jpc.12254.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3, 77-101. Retrieved from http://eprints.uwe.ac.uk/11735/2/thematic_analysis_revised.
- Creswell, J. (2007).*Qualitative Inquiry and Research Design. Choosing Among Five Approaches.* London: Sage.
- Department of Health. (2015). *Transforming care for people with learning disabilities- Next Steps.* London. Department of Health. Retrieved from https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxtstps.pdf.
- Emerson, E., Baines, S., Allerton, L., & Welch, V. (2012). *Health inequalities and people with learning disabilities in the UK.* Improving health and lives. Learning disability observatory. Retrieved from https://www.improvinghealthandlives.org.uk/publications/1165/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2012

- Glenton, C., Colvin, C.J., Carlsen. B., Swartz,A., Lewin.S., Noyes, J., & Rashidian, A.(2013). Barriers and facilitators to the implementation of lay health worker programmes to improve access to maternal and child health: qualitative evidence synthesis. *Cochrane Database of Systematic Reviews (10).* Doi: 10.1002/14651858.CD010414.pub2.
- Guba, E. G. & Lincoln, Y. S. (1989). *Fourth Generation Evaluation*. Newbury Park, CA and London: Sage.
- Jan, J. E., Owens, J. A., Weiss, M. D., Johnson, K. P., Wasdell, M. B., Freeman, R. D., & Ipsiroglu, O. S. (2008). Sleep hygiene for children with neurodevelopmental disabilities. *Pediatrics, 122*(6), 1343-1350. doi: 10.1542/peds.2007-3308.
- Kennedy, L.A., Milton, B., & Bundred, P. (2008). Lay food and health worker involvement in community nutrition and dietetics in England. Roles, responsibilities and relationships with professionals. *Journal of Human Nutrition and Dietetics, 21* (3), 210-224. doi: 10.1111/j.1365-277X.2008.00876.x.
- Malow, B. A., Adkins, K. W., Reynolds, A., Weiss, S. K., Loh, A., Fawkes, D., & Clemons, T. (2013). Parent-based sleep education for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(1), 216-228. doi:10.1007/s10803-013-1866-z
- Mason, J. (2007). The provision of psychotherapy to people with intellectual disabilities. An investigation into some of the relevant factors. *Journal of Intellectual Disability Research, 51,* 3, 244-249. doi: 10.1111/j.1365-2788.2006.00867.x
- Mason, J., & Scior, I. (2004). 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities, 17,* 2, 86-96. doi: 10.1111/j.1360-2322.2004.00184

- McDaid,C., & Sloper, P. (2009). *Evidence of effectiveness of behavioural interventions to help parents manage sleep problems in young disabled children: A rapid review*. York: Social Policy Research Unit.

- McDougall, A., Kerr, A. M., & Espie, C.A. (2005). Sleep disturbance in children with rett syndrome: A qualitative investigation of the parental experience. *Journal of Applied Research in Intellectual Disabilities, 18,* 201-215. doi: 10.1111/j.1468-3148.2005.00220.x
- Minvielle, E., Waelli, M., Sicotte, C., & Kimberly, J, R. (2014). Managing customization in health care. A framework derived from the service sector literature. *Health Policy, 177,*216-227. doi: org/10.1016/j.healthpol.2014.04.005
- National Institute for Health and Care Excellence (NICE). (2013). *Autism: The management and support of children and young people on the autism spectrum. (National clinical guideline no. 170)*. London: British Psychological Society and the Royal College of Psychiatrists. Retrieved from https://www.nice.org.uk/guidance/cg170/evidence/autism-management-of-autism-inchildren-and-young-people-full-guideline-248641453
- Piazza, C. C., Fisher, W. W., & Sherer, M. (1997). Treatment of multiple sleep problems in children with developmental disabilities: Faded bedtime with response cost versus bedtime scheduling. *Developmental Medicine and Child Neurology, 39*(6), 414-418.
- Reason, P., & Bradury, H. (2001). Introduction: Inquiry and participation in search of a world worthy of human aspiration. In P. Reason, H. Bradbury (Eds.), *Handbook of action research* (pp.1-14). London: Sage.
- Richdale, A., Francis, A., Gavidia-Payne, S., & Cotton, S. (2000). Stress, behaviour, and sleep problems in children with an intellectual disability. *Journal of Intellectual and Developmental Disability*, 25 (2), 147-161.doi:.org/10.1080/13269780050033562.

- Sasseville, A., Paquet, N., Sevigny, J., & Hebert, M. (2006). Blue blocker glasses impede the capacity of bright light to suppress melatonin. *Journal of Pineal Research, 41*, 77-78.doi 10.1111/j.1600-079X.2006.00332.x.
- The King's Fund, (2014). *Experience based co-design toolkit.* Retrieved from The King's Fund website: http://www.kingsfund.org.uk/projects/ebcd.
- Tietze, A., Blankenburg, M., Hechler, T., Michel, E., Koh, M., Schluter, B., & Zernikow, B.(2012). Sleep disturbances in children with multiple disabilities. Sleep Medicines Review, 16 (2), 117- 127. doi:10.1016/j.smrv.2011.03.006.
- Vriend, J. L., Corkum, P. V., Moon, E. C., & Smith, I. M. (2011). Behavioral interventions for sleep problems in children with autism spectrum disorders: Current findings and future directions. *Journal of Pediatric Psychology, 36*(9), 1017-1029. doi: 10.1093/jpepsy/jsr044.
- Weiskop, S., Richdale, A., & Matthews, J. (2005). Behavioural treatment to reduce sleep problems in children with autism or fragile X syndrome. *Developmental Medicine and Child Neurology, 47*(2), 94-104. doi: 10.1111/j.1469-8749.2005.tb01097.x